

**UNITED STATES DISTRICT COURT
NORTHERN DISTRICT OF ILLINOIS
EASTERN DIVISION**

Stanley Ligas, et al.,

Plaintiffs,

v.

Theresa Eagleson, et al.

Defendants.

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Case No. 05 C 4331

Judge Sharon Johnson Coleman

**PLAINTIFFS' MEMORANDUM ON CONSENT DECREE ISSUES REQUIRING
CONTINUED COURT OVERSIGHT**

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**PLAINTIFFS' MEMORANDUM ON CONSENT DECREE ISSUES REQUIRING
CONTINUED COURT OVERSIGHT**

I. Introduction

On June 15, 2023, the Court ordered the Monitor to file a report discussing the “original scope of the case, class, and consent decree; an explanation of the current issues facing the parties which justify that the consent decree remain open; and the Monitor's recommendations regarding who belongs in the class and how to address these relevant issues.” Order, June 15, 2023, ECF No. 806. The filing date was later extended. Plaintiffs accordingly submit this Memorandum.

In the 12 years since the Court entered the *Ligas* Consent Decree (Decree), considerable progress has been made, and yet more remains to be done to fulfill its terms. Through moving people out of private Intermediate Care Facilities for People with Intellectual Disabilities (ICF/DD), uncapping the number of people served through crisis funding, and providing services to people selected from the State’s PUNS waiting list, the State has served almost 13,000 Class Members. The State has also reduced the time people spend on the PUNS waiting list.

While Plaintiffs welcome this progress, serious problems remain. The State continues to engage in practices that violate the Decree and the rights of Class Members, at times endangering their lives. This includes failing to develop and provide sufficient community services for Class Members with higher needs or who are in crisis, often resulting in their being sent to State Operated Developmental Centers (SODCs) or languishing in other inappropriate settings, and failing to provide timely and appropriate community services for Class Members who are living in the community. So long as these Decree violations persist, Class Members require the oversight of both the Court and the Monitor.

II. Scope of the Class, Case, and Consent Decree

A. National Trend Towards Community Living

Illinois has failed to follow the national trend towards community living. The widespread movement to establish the right of people with disabilities to live in the community began in the late 1960s, modeling itself after the Civil Rights Movement.¹ People with disabilities made known they did not want to be sent away to live in institutions, separated from family, friends, and the life of the community.² The passage of Section 504 of the Rehabilitation Act of 1974, 29 U.S.C. § 794, was one of the Movement’s early victories. It requires states to provide services in the “most integrated setting appropriate to the person’s needs.” 45 C.F.R. § 84.4(b)(2) (2023). In 1981, Congress passed legislation allowing Medicaid to pay for community services. 42 U.S.C. § 1396n. This incentivized states to serve people with disabilities in the community. Many states responded by moving institutionalized people into small community settings. More progress was made as many states voluntarily, or as the result of lawsuits, closed SODCs, decreased reliance on private institutions, and offered increasing numbers of people with intellectual and developmental disabilities (IDD) the option to receive services in the community. *See* Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 Cardozo L. Rev. 1, 22–29 (2012).

The movement towards community living gained dramatic momentum through the passage of the Americans with Disabilities Act (ADA) in 1990, 42 U.S.C. § 12101, and the Supreme Court’s 1999 decision interpreting the ADA, *Olmstead v. L.C. ex rel. Zimring*, which held that unnecessary institutionalization is a form of discrimination. 27 U.S. 581, 600–01 (1999). Ignoring

¹ Yongjoo Jeon & Donald P. Haider-Markel, *Tracing Issue Definition and Policy Change: An Analysis of Disability Issue Images and Policy Response*, 29 Pol’y Stud. J. 215, 218–19 (2001).

² Carrie Griffin Basas, *Olmstead’s Promise and Cohousing’s Potential*, 26 Ga. St. U. L. Rev. 663, 669–670 (2010).

clear direction from Congress and the Supreme Court, Illinois stubbornly clung to its antiquated institutional system.

B. Lack of Progress Towards Community Living in Illinois and Filing of *Ligas*

As of 2005, Illinois still relied heavily on institutionalization as its primary way of providing services, embracing segregation as an acceptable and even preferred way of providing services to people with IDD. *See infra* at 15–17.³ Illinois’ insistence on institutionalizing people with IDD led to the filing of the *Ligas* class action by nine representative plaintiffs.

When *Ligas* was filed, *Ligas* Class Members were either institutionalized in private ICF/DDs or were at risk of being institutionalized.⁴ The only “choice” the State would offer for people with IDD who needed services was institutionalization, either in ICF/DDs or SODCs. Rarely would the State offer the choice that most Illinoisians with IDD wanted — to receive services in the community, to be integrated with non-disabled people, and to have the ability to enjoy the freedoms and benefits of community living. The State also capped the number of crises that it would fund per month, regardless of how dire the crises were. The purpose of the case was — and remains — to ensure that people with IDD have a real and meaningful choice to receive services in the community. Specifically, the *Ligas* Complaint sought a determination from the Court that the State was violating federal law by unnecessarily segregating Class Members in institutions. The lawsuit sought changes to the system that would ensure people with IDD had timely access to home and community-based services and were not institutionalized in private ICF/DDs due to a lack of adequate and appropriate community-based supports.

³ See also John Agosta et al., *Illinois at the Tipping Point*, Human Serv. Rsch. Inst. at iii (2012); Nat’l Council On Disability, *Olmstead: Reclaiming Institutionalized Lives (Abridged Version)* 129 (2003).

⁴ With both an institutionalized class and an at-risk class, the original case was wide spanning in its coverage. It did not, however, include residents of SODCs.

III. Current Issues Facing the Parties Which Justify the Consent Decree Remaining Open, Including Issues Related to Class Member Definition

A. The Standard for Decree Termination

The Decree provides that “The Court will grant Defendants’ Termination Request and terminate the monitoring process if the Court finds that Defendants have substantially complied with the terms of the Decree and the Court determines that Defendants have implemented and are maintaining a system that complies with the Decree.” Consent Decree, ¶ 49.⁵ The State’s performance in several critical areas remains well below what the Decree requires.

Defendants have failed to develop a robust system of community-based resources and living arrangements as the Decree requires in Paragraphs 4 and 21. This has deprived people with higher needs and people in crisis of the services mandated by the Decree. Because Defendants have not developed appropriate resources for these Class Members, Defendants place them in SODCs, a betrayal of the Class Members and a serious violation of the Decree. Defendants have placed hundreds of Class Members in SODCs over the last six years, and the consequences have been dire. Class Members in SODCs have died, been raped, and been physically and mentally abused. As for Class Members living in Community Integrated Living Arrangements (CILA), serious deficiencies persist in the quality of services Defendants provide. Simply put, the State has not yet achieved substantial compliance under the Decree.

⁵ Cases involving systemic change for people with IDD may require particular care. *See, e.g., LaShawn A. ex rel. Moore v. Fenty*, 701 F. Supp 2d 84, 112–115 (D.D.C. 2010), *aff’d sub nom. LaShawn A. ex rel. Moore v. Gray*, 412 Fed Appx. 315 (D.C. Circuit 2011) (court declined to terminate the decree or set a timeline for doing so where defendant had neither achieved substantial compliance nor established a durable remedy); *Evans v. Fenty*, 701 F. Supp. 2d 126, 171–6 (D.D.C. 2010) (court denied motion to terminate consent decree to improve services for people with developmental disabilities where defendants had neither complied with the decree, nor established a durable remedy); *Homeward Bound, Inc. v. Oklahoma Health Care Auth.*, No. 91-5006, 196 F. App’x 628, 630 (10th Cir. 2006) (originally filed in 1985 and not closed until 2012); *Jackson v. Los Lunas Ctr. for Persons with Disabilities Mexico*, No. CV 87–839, 2022 WL 1240483, at *2 (D.N.M. April 27, 2022) (filed in 1987 and not closed until 2022).

B. The State’s Failure to Develop Resource Capacity for and Adequately Serve People with Higher Needs

1. Ongoing Violation of Paragraph 4 for Higher Needs Class Members

Paragraph 4 of the Decree is dedicated to “Development of Resource Capacity.” It requires Defendants to honor “the choices of . . . Class Members, to receive Community-Based Services or placement in a Community-Based Setting.” To effectuate this obligation, Defendants must “implement sufficient measures to ensure the availability of services, supports and other resources of sufficient quality, scope and variety to meet their obligations to such Individuals under the Decree and the Implementation Plan consistent with such choices.” *Id.* ¶ 4.

The State has not met its obligations under Paragraph 4, as it has failed to develop Community-Based Settings for many Class Members who have higher needs. These are Class Members who, as part of or in addition to their IDD, have complex medical support needs, insulin dependent diabetes, high behavioral support needs, autism, or are deaf or hard of hearing, are blind, or have mobility support needs. *See* Ct. Monitor’s 2d Br. in Resp. to June 15, 2023 Status Conference 18, ECF No. 808. The Court has often referred to *Ligas* Class Members as vulnerable people; these individuals are generally the most at risk among Class Members.

The dearth of needed services is well documented. The State hired the University of Illinois at Chicago’s Institute of Disability and Human Development (IDHD) to analyze gaps in Illinois’ community-based system. IDHD’s report was issued in July 2022.⁶ The report confirmed that providers, people with IDD, guardians, and other stakeholders agree that people with higher needs are not adequately served by Illinois’ community services system.⁷ The report found that the

⁶ Crabb et al., Inst. on Disability & Hum. Dev., *An Evaluation of Community Capacity Barriers and Opportunities for Expansion in Illinois for Adult DD Waiver Services* (2022), <https://www.dhs.state.il.us/page.aspx?item=144695>.

⁷ *See id.* at Results.

ongoing challenges to supporting people with higher needs included shortages in funding, staffing, and housing; over-reliance on and high funding of SODCs; and guardians.⁸ Yet most of the steps the State intends to take to address these capacity issues involve the same ineffective strategies it has used for years, such as talking to and training providers about accepting more people with higher needs. Defendants have even refused to take the essential step of setting a floor for what Direct Support Professionals (DSPs) must be paid. Over Plaintiffs' objections, Defendants included these worn-out strategies in the 2024 Implementation Plan.

2. *The Harm to Higher Needs Class Members*

The State's failure to develop sufficient Community-Based Settings for Class Members with higher needs has resulted in enormous suffering for them and their families. Had the State used the last 11 years (and especially the last six years, since the Court's 2017 finding of noncompliance) to develop such services, supports, and resources, Class Members today would be able to access the community in a timely way.

Many Class Members with higher needs remain in the family home with aging or ill caretakers, or with inadequate supports, despite having been selected from the PUNS list or approved for crisis funding under Paragraph 21 and having chosen placement in a Community-Based Setting. The State regularly advises these Class Members and their families that there is no community provider that wants to serve them due to their higher needs and that their only choice is to go into an institution or wait things out with inadequate supports. Some of these parents and guardians choose to continue to keep their loved one at home, even at great risk for them and the Class Member, as they are so frightened of what might happen in an SODC. This group — people

⁸ *See id.*

living in the family home and unable to obtain Community-Based Services — consists almost entirely of Class Members who have higher needs.

When a higher needs Class Member's home situation finally becomes too unstable or is lost (as where the family caretaker dies, becomes homeless, or enters a nursing facility), the State — once again relying on the refrain that there are no providers that want to take them — sends Class Members with higher needs to SODCs or other institutions, often with disastrous results.

Other impacted Class Members are those who chose and were placed in the community (usually CILA), but then developed higher needs, resulting in the provider no longer willing to serve them—and the State not finding another provider in replacement. Examples include people who developed mental illness, insulin-dependent diabetes, or experienced a stroke.

3. *Defendants Cannot Excuse or Deny the Violations as to Higher Needs Class Members*

Defendants have offered various excuses for the harm higher needs Class Members are suffering as the result of the inadequate array of community-based services. None have merit.

The State asserts that Class Members with higher needs who enter SODCs are all “temporary” residents, yet most Class Members admitted to SODCs from the family home have been there for years. Since 2017, the State has admitted 559 people into SODCs⁹ and has discharged only 80 of those people (with 10 more who died in SODCs). There is now a pipeline to get out. Some of the 559 people in SODCs were Class Members living in the family home.

The State also maintains that SODC residents with higher emotional or behavioral needs must show they are “better” before they can leave, yet many will never get “better” in a large, segregated facility, especially with the lack of treatment, lack of activity, and rampant abuse and

⁹ Defendants claim that only 250 of the 559 individuals admitted to SODCs since 2017 are Class Members. Plaintiffs dispute the accuracy of this calculation and believe the number is significantly higher. Either number is unacceptable.

neglect found in Illinois' SODCs. Quite the opposite — many Class Members have dramatically deteriorated, making their chance of transition even lower. Moreover, the lack of resources that led to Class Members being sent to the SODC has not been addressed, making it unlikely that community placement will be offered.

The State also asserts that, for higher needs Class Members who have been involuntarily discharged from a CILA or other Community-Based Setting, it was consistent with the Decree for the Class Member to be sent to an SODC. That is categorically wrong and is based on a tortured reading of the Decree. Citing Decree Paragraph 21, the State contends that a Class Member who is discharged from a setting other than their family home due to a crisis is not entitled to “crisis” services and can be forced into institutional settings. Plaintiffs agree that these Class Members do not fall under the crisis provisions of Paragraph 21. But their placement in the SODC is nonetheless in direct violation of the Decree; these Class Members are protected by Paragraph 4, which requires the State to provide adequate resources for Class Members to move to and remain in Community-Based Settings.

The State appears to read Paragraph 4 to require the State only to *move* Class Members into Community-Based Settings. If a Class Member develops additional needs that cannot be met because the State has not developed sufficient Community-Based resources, the State believes it is free to promptly move them from the Community-Based Setting into an SODC. In FY21 alone, the State removed 611 adult participants from the IDD Waiver, the primary source of community funding, when it could not find them providers. The State does not track the reason why the person lost their provider, why another provider could not be identified, or when or if the person was able to get back on the Waiver. When faced by community providers unwilling to continue to serve such individuals, the State has improperly resorted to institutional placement.

In sum, the State regularly uses SODCs for Class Members with higher needs, referring to the SODCs as a “safety net.” While the State opened the door to 650 new waiver participants last fiscal year, alarmingly it also removed 111 individuals from the waiver by placing them into its SODCs that fiscal year. Reliance on SODCs violates the Decree and is neither safe nor acceptable. In 2021, Class Member KR was served in the community but was involuntarily discharged by her provider. The State placed her in an SODC, assuring her it would be only a short stay. KR has been stuck in the SODC for over two years. She is young, energetic, wants to work, and is eager to start her life in the community. Another Class Member, OL, was selected from the PUNS waiting list, but the State did not offer him timely access to a Community-Based Setting as the Decree requires. Due to the lack of a Community-Based Setting, a court ordered him into an SODC, where he later died. Class Member HR’s community provider refused to take him back after a hospitalization, claiming that it could no longer meet his needs. Defendants could not locate another provider, so only offered HR placement at SODC. His elderly mother did not want him to go to an SODC but was unable to care for him. HR choked to death at the SODC while eating, with staff present. Sadly, there are many more incidents and stories like these.¹⁰ Exhibit A. A ProPublica Investigation in 2022 revealed “documents and interviews with current and former employees and advocates, and with residents and their guardians, revealed a systemic pattern of patient abuse, neglect, humiliation and exploitation . . . Employees have since been accused of whipping, choking, punching and raping residents.”¹¹

Through their mistreatment of people with higher needs, Defendants have created a disadvantaged “class within a class” of Class Members. The State has repeatedly said to the Court

¹⁰ See, e.g., Beth Hundsdorfer & Molly Parker, *A Disabled Young Patient Was Sent to Get Treatment. He Was Abused Instead. And He Wasn’t the Last.*, ProPublica (Sept. 2, 2022 8:00 AM), <https://www.propublica.org/article/illinois-choate-mental-health-abuse-beatings>.

¹¹ *Id.*

that failing to provide community services to the group of Class Members with higher needs is not a violation of the Decree because it is a small number of people. This is factually untrue. Neither the Decree nor federal law allow the State to serve people with higher needs in a manner that is different from the rest of the Class. States cannot treat people with more serious disabilities less favorably than people with less serious disabilities. *See Olmstead*, 527 U.S. at 598–603 (holding that the ADA prohibits discrimination among members of the same protected class); *Amundson ex rel. Amundson v. Wisconsin Dep't. of Health Servs.*, 721 F.3d 871, 874–75 (7th Cir. 2013) (class of people with developmental disabilities could state a claim based on disparate treatment from people with other disabilities); *Iwata v. Intel Corp.*, 349 F. Supp. 2d 135, 149 (D. Mass. 2004) (“Title I of the ADA prohibits discrimination amongst classes of the disabled.”).

C. The State’s Failure to Develop Resources for and Adequately Serve Class Members in Crisis

Under Paragraph 21 of the Decree, the State “shall ensure that all Class Members who are determined to be in a situation of Crisis, and who request to receive Community-Based Services and/or placement in a Community-Based Setting, receive such services and/or placement in such setting expeditiously.” Decree ¶ 21(c); Exhibit B. Expeditiously” has been defined by the Monitor as between 24 to 72 hours. *See* Ct. Monitor’s 2d Br. 7, ECF No. 808. If the State is unable to locate a Community-Based Setting expeditiously, it can provide “interim emergency services (including interim placement in an ICF-DD where no placement in a Community-Based Setting was immediately available),” but provision of such services does not resolve the Crisis or prevent the Class Member from getting services they elected. Decree ¶ 21(a). The State is out of compliance with this provision in numerous ways.

First, while it is acceptable for the State to use interim emergency services when it cannot locate a Community-Based Setting quickly enough, those services must be sufficient to ensure the

safety of the Class Member until they move into a Community-Based Setting. The State refers to interim services as “Safety Plans.” In reviewing the Safety Plans, the Court Monitor found that many plans were not sufficient to ensure safety. Ct. Monitor’s 2d Br. 9, ECF no. 808.

Second, to date the State has developed only 32 crisis beds. These are located in eight 4-person community-integrated homes across the State. They provide intensive services to people in crisis, allowing them to avoid institutionalization, and are an essential component of a Community-Based Service array. While there are plans for more homes set forth in the FY24 Implementation Plan, it will be years before they are fully developed. The impact of this failure is severe; according to Defendants, there are 126 individuals currently in crisis today who have been waiting on average 150 days for placement in a Community-Based Setting, when the agreed upon standard of expeditiously served is 72 hours. Most alarmingly, many current SODC residents are Class Members who were sent to SODCs when they went into crisis.

Third, the State engaged in a wrongful years-long practice of allowing Independent Service Coordination (ISC) agencies to place people in ICF/DDs to resolve an imminent or actual crisis without training the ISCs that these individuals remained eligible under the Decree for Community-Based Settings. The State did not even have a process for tracking these individuals to ensure their rights were protected. The ISCs closed most cases of Class Members placed in ICF/DDs, depriving them of their right to live in the community.

This practice violates Paragraph 21 and Paragraph 4. The State began this year to educate ISCs that they must continue looking for Community-Based Settings for people who go into ICF/DDs to resolve imminent or actual crises, or in situations where the person is chosen from the PUNS list, but there is no Community-Based Setting available due to higher needs. The State has not, however, agreed to do any look-back to identify people whose cases were improperly closed.

These people were denied their rights under the Decree; the State should offer them the Community-Based Setting to which they are entitled, without being placed on any waiting lists.

Yet another failure by the State in respect to crisis services, as noted in the Monitor's report, is that for several years it had been reporting crisis cases to the Monitor only *after* a Community-Based Setting had been located. *Id.* 9–10. This hid from the Monitor's scrutiny those people who had raised their hands in crisis, for whom no community services had been obtained, and who were thus improperly diverted to (and abandoned in) ICF/DDs and SODCs due to lack of other options. *Id.* As a result, the Monitor has significantly underestimated the length of time people in crisis are waiting to get into Community-Based Settings. *Id.* And now that the crisis pipeline has been revealed, the State has still not proposed an acceptable resolution to the 126 crisis cases currently pending. The State approved 201 crisis applications last fiscal year, according to its Six-Month report, so this number is not small.

The State has attempted to minimize or excuse the impact of its failure to develop Crisis resources through yet another misapplication of Decree Paragraph 21, arguing that individuals are not Class Members in Crisis under Paragraph 21 unless they asked for community services and got on the PUNS list *before* going into crisis. Per the State, it is not enough to ask for community services *at the time of* crisis. This argument is contrary to the language of the Decree, which defines as a Class Member anyone who requests community services, *see* Decree ¶ 2(a), and defines "Crisis" as "at imminent risk of abuse, neglect, or homelessness." *Id.* ¶ 21(a). There is no language in Paragraph 21 even intimating that its protections extend only to people who were on the PUNS list before going into crisis. Quite the opposite is true. Paragraph 21 uses the capitalized form of the word "Individual," defined by the Decree as: "a person in Illinois 18 years of age or older who has one or more Developmental Disabilities and

who is Medicaid-eligible.” *Id.* ¶ 3(q). Further, the State is sending many of these individuals to SODCs and has been depriving the Monitor and Class Counsel for years of this information by not including them on the list of Class Members in SODCs.

That the State is misreading Paragraph 21 is further demonstrated by the fact that its reading creates illogical and unfair results in violation of Paragraph 25 of the Decree. *Id.* ¶ 25 (“Defendants shall maintain a *fair and accessible* process by which Individuals with Developmental Disabilities or their legal guardians can affirmatively request in writing to receive Community-Based Services and/or placement in a Community-Based Setting.”). If two individuals who both recently turned 18 went into crisis, only the individual who had managed (despite the impending crisis) to get on the PUNS list immediately upon turning 18 would be considered a Class Member in Crisis. The other, based on their “failure” to get on the PUNS list immediately upon turning 18, would be considered by the State not to be a Class Member and/or not in Crisis, and thus ineligible for crisis services under Paragraph 21, despite clearly requesting community services. This reading of the Decree also discriminates against people who live in poverty, people whose first language is not English, and people who live in rural areas, as they have markedly less access to information about the PUNS list.

Finally, even for those people who the State accepts as falling under the Crisis protections of Paragraph 21 (living in the family home and on the PUNS list), it is sending many of those individuals to SODCs, again in violation of Paragraph 21, which allows temporary placement in ICF/DDs, not in SODCs. Indeed, during the negotiations of the terms of the Decree, the State never requested permission to place Class Members in SODCs. The poor conditions in the State’s SODCs have been widely reported. *See* Exhibit A. Not only do Illinois’ SODCs deprive people of basic freedoms, they also are filled with physical, sexual,

and verbal abuse. *Id.* Last week, a news outlet posted a disturbing video of staff swinging a resident by the neck using the resident's sweatshirt, resulting in a larger outcry from the public for closure.¹² Staff reported witnessing “. . . a lot of pillowcases over the heads of individuals. Strangling them. Choking them, preventing them from going to the bathroom. Taking their meals away, so that they couldn't eat.”¹³ The Mabley Center has now been on Immediate Jeopardy status twice in the past three months along with last fall, at risk of losing federal funding due to the mistreatment of its residents.¹⁴ The Kiley Center was on a trajectory towards decertification by federal funders in June 2022.¹⁵ Ludeman Center was on Immediate Jeopardy status in 2022.¹⁶ After public pressure, the State has decided to transfer some residents out of the Choate Center. The State is placing people in crisis in SODCs against the wishes of people with IDD as a result of inadequate community resources. Class Member MS became homeless with his mother last year. Instead of placing him in a Community-Based Setting as the Decree requires for those in crisis, he was arranged an appointed state guardian who easily consented to his admission to an SODC against his wishes and those of his mother. He remains there to this day despite his wish for discharge.

D. Barring the State from Using SODCs for *Ligas* Class Members

The State has urged it “has no option” other than to place certain Class Members in SODCs because there are no appropriate community services. That response is, in essence, a frank

¹² Tara Molina, Disabled Residents Allegedly Abused at Chicago Area Developmental Center, CBS News (Oct. 6, 2023), <https://www.cbsnews.com/chicago/news/disabled-residents-shapiro-center-abuse>.

¹³ *Id.*

¹⁴ Beth Hundsdorfer, *UPDATE: State-Run Developmental Center in Dixon Will Not Lose Medicare Funding Despite Citations*, Cap. News Ill. (Oct. 5, 2023), <https://capitolnewsillinois.com/NEWS/state-run-developmental-center-in-dixon-will-not-lose-medicare-funding-despite-citations>.

¹⁵ Memorandum from Kim Kilpatrick, Facility Dir., Kiley Ctr., to Families and Guardians of Residents at Ann M. Kiley Development Center (June 3, 2022).

¹⁶ Dep't Health & Hum Servs. Ctrs. for Medicare & Medicaid Servs., Statement of Deficiencies and Plan of Correction 21 (Apr. 19, 2022), <https://ltc.dph.illinois.gov/webapp/LTCApp/formatted3.jsp?eventId=KK4I11&facilityid=6002802>.

admission of Defendants’ persistent and longstanding failure to comply with the capacity-building obligation the State agreed to when it signed the Decree. The Court, along with the Monitor, found the State out of compliance with Paragraph 4 in 2017 precisely because of the State’s failure to develop sufficient resources. Defendants have yet to present any evidence that a contrary finding is appropriate today because there is none.

Once placed in an SODC, it is very difficult for *Ligas* Class Members to get out. The average length of stay for people who transition out of SODCs is around 15 years.¹⁷ Illinois invests heavily in its SODCs, diverting financial and human resources away from the community.¹⁸ The State still will not acknowledge what almost every other state has – that large institutions deprive people of their liberty, provide inferior services, and often become hotbeds of abuse and neglect. Such facilities provide “confinement and isolation, the antithesis of habilitation.” *Pennhurst*, 446 F. Supp. at 1318.

Illinois currently has about 1,622 people in SODCs¹⁹ and approximately 3,500 people in ICF/DDs.²⁰ Sadly, Illinois has more people in SODCs than *any other state* but Texas and Ohio.²¹ By comparison, Michigan has no SODCs or ICF/DDs, and Minnesota has no SODCs and about

¹⁷ Crabb et al., An Analysis of Movement from Illinois State-Operated Developmental Centers: Transitions Between July 1, 2020 – June 30, 2021, at 6 tbl.2 (2022), <https://eppu.ahs.uic.edu/wp-content/uploads/sites/773/2023/02/SODC-Transitions-Evaluation-Report-07.01.2020-06.30.2021.pdf>. This of course does not include the people who never transition out.

¹⁸ See Ill. Dep’t. Hum. Servs., FY2023 Developmental Disabilities Service Summary, <https://www.dhs.state.il.us/page.aspx?item=155188>, (last visited Oct. 12, 2023) (noting SODC expenditures of \$338,215,600).

¹⁹ See Ill. Dep’t. Hum. Servs., Transition Report by SODC as of 10/01/2023, <https://www.dhs.state.il.us/page.aspx?item=82095> (last visited Oct. 12, 2023).

²⁰ See Ill. Dep’t. Hum. Servs., Adults with Developmental Disabilities by Living Arrangement FY10 to FY23, <https://www.dhs.state.il.us/page.aspx?item=137736> (last visited Oct. 12, 2023) (subtracting the approximately 700 in MC/DD facilities from the total number of 4,200 people in ICF/DD facilities to reach 3,500).

²¹ See United Cerebral Palsy & Am. Network Community Options & Res., *The Case for Inclusion* at 12 (2022) (noting Illinois maintains seven public residential facilities, behind only Texas and Ohio).

1,000 people in ICF/DDs.²² As of 2022, 18 states and the District of Columbia have ceased operating SODCs, including Alabama, Alaska, Hawaii, Indiana, Maine, Minnesota, Michigan, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Tennessee, Vermont, and West Virginia.²³

The State's fidelity to the antiquated SODC model of care impacts *Ligas* Class Members in two ways. In the last six years, the State has sent many Class Members to SODCs, an obvious violation of the Decree. The State also continues to use lack of community capacity to defend its sending of Class Members and other people with IDD to SODCs, yet one of the reasons for lack of community capacity is the State's huge investment—capital and human—in SODCs. Illinois refuses to accept that people with IDD have full human and civil rights; these rights include living in the community; most people with IDD prefer living in the community; most people with IDD live a far better quality of life in the community; communities benefit from diversity, which should include people with disabilities; and the rights of people with IDD to live in the community are not trumped by the desires of politicians and unions to boost local economies.²⁴ Plaintiffs are deeply disturbed by the State's representations to the Court that most Class Members — by

²² See Sheryl Larson et al., Residential Info. Sys. Project, *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2019*, at 16 tbl.1.3 (2022), https://ici-s.umn.edu/files/y_7tYyJDmn/risp_2019_v6.

²³ United Cerebral Palsy & Am. Network Community Options & Res., *supra* note 21.

²⁴ See Ill. Dep't. Hum. Servs., Module 5: Community Inclusion 6–7 (2011) (listing ways in which community living benefits the individual and the community), https://www.dhs.state.il.us/onenetlibrary/27896/documents/by_division/division%20of%20dd/residential_directorcore/module5rdccommunityinclusion.pdf; Valerie J. Bradley et al., *Housing for People with Intellectual and Developmental Disabilities: How Do We Ensure a Home of Their Own?* 11 (2015) (showing approximately 80% of IDD survey respondents happy living in community-based settings versus only approximately 40% content in institutional setting), https://legacy.nationalcoreindicators.org/upload/presentation/Housing_NASDDDS_final.pdf; Nat'l Council on Disability, *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community* 23 (2015) (noting a clear trend in a metanalysis of 45 peer-reviewed articles that “people with disabilities living in smaller settings are more likely to achieve positive outcomes and to experience an improved personal and support-related quality of life than are individuals who live in larger settings”), https://ncd.gov/sites/default/files/HCBS%20Report_FINAL.pdf.

definition, people who have expressed a desire to live in the community — have gone to and remain in SODCs by choice. The State offered these individuals no option other than SODCs.

E. The State's Failure to Provide Adequate Services to Class Members Who Have Moved to the Community

Six years ago, on August 11, 2017, this Court granted Plaintiffs' and Intervenor's Joint Motion to Enforce the Consent Decree. Order, Aug. 11, 2017, ECF 695. The Plaintiffs and Intervenor submitted extensive evidence in support of the motion, including affidavits from service providers, Class Members, guardians, and relatives. They also relied on the Monitor's Report from January of the same year, which found Defendants out of compliance with the Consent Decree. *See* Monitor's 5th Annual Report 6, 30, Jan. 20, 2017, ECF 646. All the evidence pointed to the same ineluctable facts, including: the State was continuing to underfund both the DD community system and the ICF/DD system, while robustly funding its SODC system; wages for DSPs in CILAs and aides in ICF/DDs were so low that almost all providers had high staff vacancy and turnover rates; SODC wages for the same positions were almost twice as much as those in CILAs and ICF/DDs; Class Members were typically living in CILA homes larger than they wanted due to funding and staffing issues; many small CILA homes were being merged due to funding and staffing issues; both CILAs and ICF/DDs had safety issues due to funding and staffing issues; both CILAs and ICF/DDs had incidents of medical neglect due to funding and staffing issues; and community recreation and employment opportunities were minimal due to CILA staffing and funding issues. *See id.* at 3–6.

In the six years since the Court's granting the Motion to Enforce, the State has still not made sufficient improvements to come into compliance, as evidenced by, among other things, the lack of community providers for people in crisis and people with higher needs. While the State has increased funding in the community system (and also for ICF/DDs), the State has set no minimum

that providers need pay DSPs other than the State's minimum wage; this practice seems wholly inconsistent with the Court's repeatedly expressed concerns about low wages for DSPs and the corresponding high vacancy and turnover rates. Moreover, community rates are still a fraction of SODC rates. The State is quite willing to fund SODCs annually at \$350,000 per person — despite the abuse, neglect, isolation, lack of treatment, lack of activity, and, perhaps most serious, the lack of liberty and community integration endemic to Illinois' SODCs — and to send *Ligas* Class Members there, in direct contravention of the Decree. Yet, average community rates are less than a third of the SODC rate. Providers have indicated a desire to play a larger role in transitioning Class Members out of the SODCs, but advise that rates are too low to allow transition.

In the Monitor's most recent survey of community services, quality indicators rose significantly, showing the ability of community providers to improve their services. Indeed, even with low rates, Illinois' community living system measures higher on virtually every measure than SODCs. But the quality indicators are still nowhere near where they should *and could be*, were the State to put appropriate money and monitoring into the community system. In the 17 categories that the Monitor considered, eight were at 85% compliance or higher, a clear improvement from the last review, when none of the scores reached 85%. *See* Monitor's 1st Br. in Resp. to June 15, 2023 Status Conf. 34–35. But the nine that are not in compliance reflect worrisome deficiencies.

Person-Centered Planning (PCP) received a score of 72% and Independent Service Coordination (ISC) received a score of 68%. *Id.* Both form the map for community living. *See id.* at 7–12, 33–34. The PCP process identifies the needs, wants, and goals of the individual; ISC's guide the planning process and locate the services needed to make the plan a reality. *See id.* These low scores are of great concern, as they show that about one-third of Class Members are not getting services consistent with their needs, wants, and goals. The State has spent enormous time and

energy in creating a good process; now it needs to ensure that the process is followed. These failures violate Paragraphs 4, 5, and 14.

Other quality measures assessed by the Court Monitor are of equal concern. Community integration/access to the community and a meaningful day — the core value of this case — had only a 53% score. Monitor’s 1st Br. at 15–18, 35. Access to occupational and physical therapy was at the same exceedingly low score as the last review — 29%. *Id.* at 24–25, 35. Continued oversight by the Monitor and Court is thus required to ensure that the State improves the quality of community services and maintains those improvements.

IV. Moving Forward Toward Termination of the Decree

As was true when the Court found the State out of compliance in 2017, the State has failed to develop and maintain a robust community system for people with IDD and especially for those who have higher needs and/or are in crisis. States with far fewer economic resources than Illinois serve people in the community, even when they develop higher needs or are in crisis. The terms of this Decree, all of which the State agreed to, could be readily achieved if the State would prioritize the right of people with IDD to live in the community.

These deficiencies must be corrected before serious thought can be given to ending the oversight of the Court and the Monitor. In a similar lawsuit, the U.S. Department of Justice in 2012 alleged that the State of Virginia failed to serve individuals with IDD in the least restrictive setting.²⁵ In 2020, the parties jointly filed a set of compliance indicators after the Court ordered them to develop measures that would state the precise terms of compliance.²⁶ In 2023, the court

²⁵ Complaint at ¶ 26, ECF 1, *United States v. Commonwealth*, 3:12CV00059 (E.D. Va. filed Jan. 26, 2012)

²⁶ Joint Filing of Complete Set of Agreed Compliance Indicators Attachment 1, ECF 364-1, *United States v. Commonwealth*, 3:12CV00059 (E.D. Va. filed Jan. 26, 2012).

monitor used those compliance indicators to objectively assess compliance, and the parties are on a more direct path to exiting the decree.²⁷

The Parties have not developed compliance indicators for *Ligas*. Defendants are under two other consent decrees in the Northern District involving similar ADA violations in nursing facilities and mental health facilities.²⁸ In those cases, the parties are developing compliance indicators, to lead to compliance with the decrees and closure of the cases. Early in *Ligas*, the original court monitor developed quality indicators for Class Members residing in CILAs; these are used by the current *Ligas* Court Monitor to help provide an objective measure of whether Defendants are complying with portions of the Decree specific to quality of services in the community. Plaintiffs support developing, with the expertise of the Court Monitor, compliance indicators on the issues raised in this memorandum (and anything else required to exit this Decree) to provide benchmarks and clear expectations, ensuring both parties have a well-articulated road map for achieving compliance.

V. Conclusion

For all these reasons, Plaintiffs respectfully ask the Court to continue its oversight of the Consent Decree and to direct the Monitor and Parties to develop mutually acceptable Compliance Indicators.

²⁷ See Report of the Independent Reviewer on Compliance with the Settlement Agreement 3–6, ECF 448, *United States v. Commonwealth*, 3:12CV00059 (E.D. Va. filed Jan. 26, 2012). See also U.S. Submission Pursuant to September 21, 2023 Order Regarding Court's Next Steps and Oversight 2–4, ECF 468 (E.D. Va. filed Jan. 26, 2012) (outlining the need for ongoing judicial oversight).

²⁸ See Consent Decree, ECF 210, *Colbert v. Pritzker*, No. 1:07-CV04737 (N.D. Ill. filed Aug. 22, 2007); Consent Decree, ECF 326, *Williams v. Pritzker*, 1:05-CV-04673 (N.D. Ill. filed Aug. 15, 2005).

Respectfully submitted,

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